

## **Testimony**

### **Anonymous**

May 10, 2011

To the Members of the Chronic Fatigue Syndrome Advisory Committee:

In 1994, I was a healthy 20-year-old college student who led an active, happy life. One afternoon in June, I was struck down by ME/CFS. Over the years I got gradually worse until I became essentially bedbound in 1999 and again in 2005. My plans for graduate school, a career, marriage, and children have been on hold for 17 years..

I think there is a common misconception, even among doctors and researchers well-versed in ME/CFS, that this illness is not especially disabling. Even if they are unable to work, the thinking goes, most patients are able to take care of their basic needs and engage in activities of daily living.

That's not the case for me and many people I know. Due to my extreme post-exertional fatigue, muscle weakness, and orthostatic intolerance, I'm forced to spend 95% of my time lying on my back on this mattress in my small bedroom with one window. I haven't been able to take a shower since 2005—not even with the help of a shower chair. I bathe and clean my teeth in my bed. Once a month my elderly mother washes my hair for me in the bathtub.

My parents bring all of my meals to my room on a tray. If I want to go to another upstairs bedroom I have to be pushed in my wheelchair. I haven't been able to go downstairs or outside since November. I've gone years at a time unable to leave my home, even to see a doctor. I've had periods of being incapable of feeding myself. I spend my worst days immobilized and unable to think, watching my bedroom get light, then dark, then light again. Outside my window, the seasons change, over and over.

My incapacity is not unique. One of my friends with ME/CFS hasn't been able to leave her home in seven years and can't walk; she uses an electric wheelchair to get to the bathroom. Another needed a catheter in her bladder because she couldn't get up at all. Other friends are so weak that they can't lift a cell phone or speak above a whisper. I'm lucky that my parents are supportive; some of the worst off

have no financial or physical help from their families. This intersection of severity and poverty turns their lives into a hellish struggle for food, shelter, and other basics of survival.

As severely ill as my friends and I are, many people are considerably worse off. At least I can type a little bit, lying down, and talk on the phone a couple times per week. But some patients have virtually no contact with other human beings or the outside world; their minds are too weak to hold a thought or to interact. They spend their years in an abyss of isolation and suffering.

How many patients are like me or worse? No one knows, because our government and advocacy groups have never studied us. Most doctors don't know we exist because we have extreme difficulty going to their offices. We are excluded from virtually every research study, meeting and conversation about this disease.

Despite the realities imposed by severe ME/CFS, our government and even our largest advocacy group continue to portray this illness as a relatively benign condition that might slow people down for a few years, but otherwise isn't a big deal. Average patients, according to them, should be able to undergo the CDC's recommended treatments--exercise and psychotherapy—in addition to caring for themselves and maybe even working part-time.

For me, exercise is changing my nightgown. And the exertion of leaving my home for psychotherapy sessions—transported lying down—would set me back so far that I might not be able to lift a glass of water for a year.

Our government so devalues this illness that it spends 100 times more per capita on MS research than it does on ME/CFS research. As I struggle to brush my teeth and walk a few steps to the bathroom or bedside commode, I remember that our government considers my life only 1% as valuable as the life of someone with MS.

The government claims that ME/CFS is a poorly-defined condition, but surely I have as many abnormal test results as an MS patient: an abnormal SPECT scan; a LMW protein in RNase-L; undetectable IgA and low IgG3; POTS/NMH; and evidence for numerous infections (Lyme, Bartonella, Babesia, Erlichia, Mycoplasma, C. pneumoniae, EBV, and HHV6-B). I am also XMRV-positive.

On behalf of all the severely ill patients who can't represent themselves at CFSAC or anywhere else, I ask you to pass vigorous resolutions on the following issues:

1. The International Classification of Diseases must accurately categorize CFS. This is an extremely urgent matter because the draft proposal is due to become final within months. The International Classification of Diseases 9 Clinical Modification (ICD-9-CM), currently used in the United States, will become the ICD-10-CM in 2013 and remain our country's medical bible for years or decades. Unfortunately, the draft proposal for the new edition continues to place CFS in a wastebasket section of the ICD for "ill-defined conditions". Another problem is that CFS will be renamed to CFS NOS (Not Otherwise Specified) . Excluding CFS from classification as a neurological disease under G 93.3, and renaming it CFS NOS, perpetuate the myth that CFS is a vague, poorly-defined non-disease. These actions may cause us to be labeled as hypochondriacs or malingerers, may adversely affect our insurance and disability payments, and will undermine research efforts into biomedical causes of CFS.

You must strongly advise that the CDC reclassify CFS as a neurological disease under G 93.3, the code used for CFS by the rest of the world in their versions of the ICD. Secretary Sebelius must be made aware that this is a serious issue with a looming deadline. Furthermore, please discuss additional means of pressuring the CDC to recode CFS under G 93.3.

2. In the name of equal rights for equal disability , you must pass a resolution seeking parity in funding for ME/CFS research. ME/CFS should receive funds from Congress commensurate to the serious nature of the disease, and equivalent to what is received by similarly disabling illnesses, like MS. Asking for \$100 million in funds would be a step toward righting the current gross disparity in research dollars.

3. The NIH has rejected every grant proposal from the Whittemore Peterson Institute since the publication of its landmark paper in *Science* linking ME/CFS to the retrovirus XMRV. Please pass a resolution stating that this is unacceptable, and investigate why this has occurred. Is it because the Special Emphasis Panel responsible for reviewing ME/CFS grants is composed of so many dentists, psychiatrists and psychologists? If so, the review process for ME/CFS grants needs to be changed, perhaps by moving ME/CFS research out of the ORWH to NIAID.

4. Please resolve that the use of the Empirical Definition (Reeves Criteria) in research is absolutely unacceptable and should not be funded by the United States government. The Empirical Definition does not correspond to any disease entity but to a hodgepodge of psychiatric conditions, simple tiredness and unwellness.

Research based on this definition, which grossly inflates the number of Americans with CFS, is virtually meaningless. Furthermore, please advise the CDC and NIH to adopt the Canadian Consensus Criteria, or the equivalent, as the its official ME/CFS definition.

Thank you. It will take me a week to recover from writing this letter, which was the only activity I could manage for several days.

Sincerely,

Anonymous